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Title: Factors Related to Nonadherence of a Low Sodium Diet in Heart Failure Patients

Running Title: Sodium Nonadherence

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Background: A low sodium diet is a cornerstone of nonpharmacologic therapy for heart failure patients. Although nonadherence is common, little is known about why heart failure patients fail to adhere to this diet. The purpose of this study was to explore the experience of heart failure patients in following a low sodium diet.

Methods: We conducted a qualitative descriptive study with a convenience sample of 20 participants. Interviews were conducted and analyzed for themes.

Results: The data reflected three primary themes about nonadherence to the low sodium diet: lack of knowledge, interference with socialization, and lack of food selections. Participants expressed a need for details about dietary information, low sodium food selection, food preparation, and rationale for the diet. Lack of knowledge also was manifested as diet confusion for participants who required additional dietary restrictions related to other disease processes. Interference with socialization was manifested by patients' experiences with family conflict when family members chose and ate high-sodium foods at home or family gatherings, and difficulty eating out. The theme of lack of low sodium food selections was reflected by comments about limited food choices, and lack of palatability.

Conclusions: Researchers and clinicians need to consider patients' perceptions as they generate and evaluate interventions to increase adherence to a low sodium diet.

Key Words: Dietary sodium, adherence, qualitative research

Over 4,900,000 Americans have heart failure (HF), a chronic illness that contributes to more than 262,000 deaths annually.[1] Each year approximately 400,000 to 700,000 new patients are diagnosed with HF.[1] The United States spends $24.3 billion annually to care for persons with HF.[1] Approximately 60% of this cost is for hospital care.[2] The most common cause of HF hospitalizations is volume overload, and the proximate cause of volume overload in most cases is excessive dietary sodium intake.[3-5]

Since 1995, much progress has been made in improvement of pharmacologic and nonpharmacologic therapies for HF.[6] Physicians and nurse practitioners often prescribe multifaceted medical, dietary, and exercise treatment regimens for individuals with HF. The low sodium diet is a cornerstone of nonpharmacologic therapy.[6] However, nonadherence to this component of HF therapy is extremely common.[3-5,7,8] Despite the low rates of adherence to the low sodium diet recommendation, little is known about why patients with HF fail to adhere. Accordingly, the purpose of this qualitative descriptive study was to explore the experience of HF patients as they attempt to follow a low sodium diet.

Methods

Design

A qualitative descriptive approach guided this research.[9] This design is appropriate when the goal is to describe a phenomenon using a common language that clinicians will understand. "Qualitative description is especially amenable to obtaining straight and largely unadorned...answers to questions of special relevance to practitioners and policy makers."[9]

Participants and Setting

Using convenience sampling, 20 patients who met the following criteria were enrolled in this study: 1) diagnosis of HF due to left ventricular systolic dysfunction with ejection fraction less than 50%, 2) healthcare provider's recommendation to follow a low sodium diet, 3) no

cognitive impairments limiting the ability to complete an interview, 4) not living in an extended care facility, and 5) on stable medical therapy without major recent adjustments. All patients spoke English and received care at a HF clinic located in a major Southern academic medical center. **Table 1** contains information regarding the characteristics of the sample.

The Institutional Review Board approved this study and this investigation conforms with the principles outlined in the Declaration of Helsinki. Prior to data collection, participants gave informed, written consent for this study.

Data Collection

The investigators collected data regarding demographic and clinical characteristics by patient interview and medical record review. The investigators contacted potential participants in person or by telephone and invited them to participate in this study. The patient and investigators scheduled the interview for a mutually agreeable date, time, and place. Before the first interview, the investigators designed an interview guide that facilitated a consistent approach to each interview. An expert qualitative researcher reviewed the interview guide and study protocol. The semi-structured interviews took place in a private room in the clinic or at the patient's home, ranged from 20-50 minutes in length, and occurred during the spring and summer of 2003. Seven participants were interviewed at home and 13 participants completed their interview in the clinic. All interviews were audiotaped and the investigators made field notes during and after each interview.

To establish rapport between the investigator and patient, the investigator began by stating, "Please tell me about your heart failure." Patients were then asked various questions regarding what diet was prescribed for their HF, how they learned about a low sodium diet, their experiences in following a low sodium diet, and factors that prevented them from following a low sodium diet. Follow-up questions were asked to clarify information or to further explore

patient-generated comments.

The investigators continued to interview patients until they achieved saturation of data and the interviews yielded no new information. Prior to coding, an experienced transcriptionist transcribed each interview verbatim; the investigators confirmed transcription accuracy by comparing each audiotaped interview with its corresponding transcript.

Data Analysis

The investigators used SPSS software, version 11.5, to summarize data regarding demographic and clinical characteristics. These results are presented as frequencies and means ± standard deviations.

The investigators used content analysis procedures to analyze interview data with the goal of accurately describing patterns or regularities within the data.[9] Prior to analysis, the investigators proposed potential codes based on their recall of the interviews. Examples of these codes were other dietary restrictions, palatability, and limited food choices. Two investigators (BB and MDJ) independently coded the transcripts, identifying recurrent codes and themes that focused on description of why patients with HF fail to adhere to a low sodium diet. During data analysis, the investigators collaboratively added or refined codes as indicated. The investigators double-coded portions of the transcripts to ensure interrater agreement. When the investigators disagreed on a code, they reexamined the transcript in detail and discussed the matter until they achieved consensus. After coding the data, the investigators collapsed similar codes into major themes. Analysis procedures were recorded in an audit trail.

Results

The data reflected three primary themes regarding reasons for nonadherence to the prescribed low sodium diet: lack of knowledge, interference with socialization, and lack of food selections.

Lack of Knowledge

The participants expressed a need for healthcare personnel to provide them with detailed dietary information and written instructions regarding low sodium food selection and preparation, but the majority stated that they did not receive this information. According to a participant, "They didn't really cover what I wanted to know. They just discharged me and that's it." Other participants easily listed high sodium foods, but paused and had difficulty naming low sodium foods. One participant stated, "I wish it would have been like when I was diabetic. They gave me a food list of what contained a lot of sugar and a diet which had cooking instructions. If you would offer some recipes that would be helpful."

Another finding emerged as it became apparent that most participants taught *themselves* about their low sodium diets. Physicians, nurses, and dieticians told them to follow a low sodium diet; however, according to the participants, these healthcare professionals provided scant details about low sodium foods and strategies for following a low sodium diet. As a result, participants taught themselves how to read food labels and independently acquired information about a low sodium diet. Several informants had previously cared for a family member who was on a low sodium diet and related that this experience eased their own transition to a low sodium diet. In spite of their efforts, participants failed to fully comprehend the intricacies of following a low sodium diet. One participant stated, "Well, the dietician gave me some points to follow, but I didn't understand them that well because I don't think she was thorough with me, so I just went with what I understood." The participant went on to say, "My sister is a nurse and…she told me what to stay away from…and she can inform me what to do."

Participants were unaware of the sodium content or the "hidden salt" in many foods. Several participants expressed pride in putting their salt shaker away, yet spoke about routinely eating high sodium foods such as bacon, canned soup, and chow mien. One participant even

asked, "But all you have to do is cook and not add any salt to it, isn't that right?"

It was evident that the participants failed to understand the rationale behind their dietary restriction. After consuming high sodium foods, patients noted increased edema and shortness of breath, but they did not attribute these symptoms to worsening cardiac function. Furthermore, participants focused their attention on these physical discomforts but did not express worry or concern about their heart. A patient's wife stated, "If he goes out and eats something that someone else cooks and it has too much salt in it, you can tell the difference. I don't know if that has anything to do with him maybe being dizzy, short of breath, and all that kind of stuff, but that might have something to do with it." This participant and his wife never mentioned that the higher salt intake might be further straining his already failing heart.

For those participants with additional dietary restrictions, following a low sodium diet was confusing. Respondents struggled to differentiate between low cholesterol and low sodium foods and often assumed that all heart healthy foods were low in sodium. A male participant stated, "Sometimes we can find bologna that is low in fat." Another said, "I bought some new butter that is supposed to have the healthier fats in it."

Interference with Socialization

Participants expressed frustration that their low sodium diet restrictions permeated their entire lifestyle. Nearly all participants identified that eating out was an obstacle to adhering to their prescribed diet. Respondents lamented that eating out was challenging because many restaurants use excessive sodium in preparing food. One participant commented, "You can't go anywhere hardly that they haven't already salted or dumped a bunch of barbeque on it…it's hard to find a place to eat…" Furthermore, participants perceived that their diet limited opportunities to socialize with friends and family. A female participant stated, "We had friends who used to come and eat with me all the time, but they don't anymore. In their opinion, I'm not as good of a

cook as I used to be."

The diet also interfered with longstanding church activities. Many participants commented on the hardship of church dinners. One participant stated, "We had an anniversary down at our church and they were fussing and mad at me because I wouldn't eat that stuff. I just couldn't eat it."

Friends and family did not always understand the participant's diet restrictions and did not respect their dietary needs. Low sodium diet restrictions directly contributed to conflict within some families. Some respondents felt isolated from family members who continued to eat high sodium foods. One participant spoke of having a problem with family members who requested specific foods, "We request things, you don't cook them anyway, so why don't you cook what you want to cook?" Another expressed bitterness towards her husband, "My husband makes it terribly hard. He doesn't consider the fact that I should not eat at certain restaurants when I'm with him."

Lack of Food Selections

Limited low sodium food choices and lack of palatability were identified as significant barriers to adherence. Participants expressed dismay that most foods contain more sodium than they are allowed to eat. A participant stated, "It just overwhelms you because you know sodium is in everything." Another informant said that she did not think following a low sodium diet would be difficult until she went shopping. She said, "I went into a store and everything I picked up had salt in it and I freaked out, sort of, I couldn't believe that so many things had salt in them. It's unbelievable."

For many participants, the problem of limited food choices was confounded by additional dietary restrictions. As a result, participants could not even eat certain low sodium foods. Participants were challenged to adhere to diet restrictions related to Coumadin therapy and

diabetes. For example, they stated that fresh fruits and vegetables contain little sodium but expressed concerns about maintaining correct blood levels of Coumadin when eating too much fresh produce. One participant's wife summarized this concept saying, "...he's a diabetic and it's double the trouble..." Another diabetic respondent stated, "I can't have a lot of fruit so that limits food choices..."

Participants complained that few low sodium foods appealed to their appetite and thus further narrowed food selection. Palatability, or the lack thereof, was a recurring issue for the participants. One patient stated, "...the green beans, to me they're very hard to eat because they're very hard to season..." Participants discussed the ongoing hardship of looking for something to replace the flavor of salt. For example, "...I tried the salt substitute but did not like it, tried Mrs. Dash but wasn't satisfied..." Many times a salt replacement was never found, "...I could do without the butter, but I just have to have a little taste of salt."

The lack of food selection was a chronic hardship. Participants expressed the need to always plan ahead. Several participants noted that the sodium content of foods is always on their minds and that meal planning requires constant attention. Several informants talked about their struggle with keeping an adequate inventory of low sodium foods at home. One informant spoke about this, saying, "Yeah, that's the problem. If I don't have it in the house, that's the reason it's all the time on your mind, all the time trying to stay ahead of it so you don't get caught in those situations. And that's why it's hard." The cravings for favorite high sodium foods never diminished. One participant commented, "I love hot dogs, a chili dog would taste so good."

Discussion

The principal finding from this qualitative study was that lack of knowledge, interference with socialization, and lack of food selections were the major reasons persons with HF did not adhere to their low sodium diet. This is one of the first qualitative studies to directly explore

reasons patients with HF do not adhere to a low sodium diet.

A unique finding from this study was that patients perceived they had received little teaching from health care professionals regarding their low sodium diet, and that they needed to take responsibility for educating themselves about their diet. This finding is surprising because of the value healthcare providers place on patient teaching. In one study, nurses reported that patient education regarding medications and diet was the most important learning topic for patients with HF.[10] Kuehneman and colleagues conducted a dietary survey of professionals from an established HF program and reported that all team members believed diet information was important.[11] Despite these findings, the data from the current study indicated that healthcare professionals' beliefs about patient education may not translate into behaviors that fully inform patients. Because patients perceived that they did not receive adequate education, more research is needed to determine whether patients truly do not receive diet education or if patient education is ill-timed, ineffective, or presented in a manner that does not promote individual learning and knowledge retention.

A number of investigators have demonstrated the importance of following a low sodium diet to the optimal management of HF. For example, Bennett and colleagues found that sodium retention was the principle reason for hospitalization of patients with HF.[3] Similarly, others reported that excessive sodium intake was the most common cause of HF exacerbation.[4] Indeed, nonadherence to diet is a major recurring theme in the literature about preventable causes of HF hospitalizations.[7,12,13] Despite the importance of the low sodium diet, there is little research to guide clinicians as they attempt to define the most effective interventions to improve adherence. Findings about the reasons for patients' nonadherence can provide a foundation for such interventions.

Although there have been few investigations of the reasons for nonadherence to the low

sodium diet, other investigators have noted some of the same reasons we found for nonadherence.[11,14] Individuals may not eat low sodium foods because they believe that these foods are less palatable or more difficult to cook.[8] In a study of 50 participants, Neily and colleagues reported that 86% of patients were unaware of a sodium restriction guideline and 42% of patients were unable to read the sodium content on a nutrition label.[15] Patients with HF are also challenged by physical limitations, negative emotions, anxiety, and diet restrictions related to other diseases such as diabetes.[16,17]

Other researchers used a qualitative method to investigate other aspects of HF and reported findings pertinent to a low sodium diet. Riegel and Carlson interviewed patients with HF to learn how HF affects their lives, assess self-care, and determine their ability to care for themselves.[17] A major finding was that many patients "were unable to judge the importance of their symptoms, misinterpreted them, or did not believe that self-care behaviors could relieve them." Additionally, patients usually did not make the connection between their nonadherence with a low sodium diet and worsened symptoms of HF.

Using a qualitative approach, Happ and associates reviewed advanced practice nurse (APN) and physician notes and patient medical records to describe factors that contribute to rehospitalization for elderly patients with HF.[8] All patients had previously received an intervention during which an APN conducted inpatient discharge planning and at least two homecare visits. Not surprisingly, patients with HF who did not adhere to their medications and diet or engaged in poor health behaviors, such as smoking, were most likely to require rehospitalization. Alternatively, motivated patients and those with a support system were less likely to require rehospitalization.

Finally, Bennett and associates conducted separate focus groups for patients with HF and their families to learn more about symptoms of HF and strategies used to manage these

symptoms.[16] Some participants recognized that excessive sodium intake resulted in dyspnea. Adherence to a low sodium diet was a major strategy that participants used to manage symptoms of HF. Other patients reported anorexia, food cravings, and weight loss as a consequence of lack of palatability of low sodium foods.

The emphasis of previous qualitative studies has been related to outcomes of nonadherence to a low sodium diet.[8,16,17] Outcomes of nonadherence to a low sodium diet have been well documented.[3-5,7] Qualitative studies related to prevention of these outcomes are needed. The first step to prevention may be open dialogue on factors contributing to nonadherence. This information is necessary to develop better preventive interventions or teaching plans to increase adherence to a low sodium diet.

In examining the HF patient teaching literature, it is probably not surprising that HF patients feel uninformed about aspects of their treatment regimen. The development of current teaching approaches and interventions has not been systematic in that studies do not build on previous research findings, many interventions used in clinical practice are not evidence-based, and patient teaching is not standardized within a single institution, let alone on a state or national level.[18-20] It may prove beneficial for researchers and clinicians to step back from current methods of teaching and reconsider their approach. The results of the few descriptive and qualitative research studies such as the current study provide a beginning foundation upon which to begin to design more effective interventions.

Results of this study suggest that patients could benefit from an intervention that provides detailed dietary information, including strategies to minimize interference with socialization and an emphasis on the availability of low sodium foods. Patients requested specific verbal and written information about low sodium foods, strategies for eating out, recipes for low sodium dishes, tips for a quick snack or meal, ways to improve palatability, and the procedure for

reading a food label. Multiple participants mentioned that they received only one teaching session. Although such a strategy is efficient for busy healthcare providers, existing evidence about effective teaching indicates that teaching should be delivered over multiple sessions to increase retention of material.[11,21] Family members should be invited to attend the educational sessions as their understanding of the diet regimen may increase patient adherence and minimize family conflict.[22] Family involvement may especially increase adherence of patients who are incapable of self-care[23] or who suffer from decreased concentration/attention span and memory loss.[16] Finally, intervention strategies that acknowledge a patient's cultural background and religious beliefs may promote adherence.

An intervention, such as the one just described, may increase patient knowledge. However, knowledge alone does not ensure a change in behavior. For example, Ni and associates interviewed patients and found that although 80% knew they should limit their sodium intake, only one third consistently avoided salty food.[12] Factors other than lack of knowledge may impact adherence. A participant in this study spoke about this saying, "We are just plain country people and we eat country food. We have been eating salt all our life." For some participants, factors other than education may influence their intention to adhere to a low sodium diet.

According to the Theory of Planned Behavior (TPB), behavioral change is a direct result of intention.[24] Intention is predicted by attitude, perceived social pressure, and perceived control. The TPB may identify factors influencing food choice and thus be a good predictor of behavior. Nguyen, Otis, and Potvin successfully used the TPB to identify the variables that influenced the intention of 30 to 60 year-old men in following a low-fat diet.[25] To our knowledge, no investigators have used the TPB to develop or test a low sodium diet intervention for patients with HF. Further qualitative studies are needed to explore psychological and

cognitive factors affecting adherence to a low sodium diet.

A limitation of this study is that all participants were recruited from one HF clinic. The participants resided throughout the state and received primary care from their local physician; nonetheless, they may not be representative of all persons with HF.

There are multiple reasons why patients with HF do not adhere to a low sodium diet. With the rising incidence of HF, it is imperative to continue to investigate reasons for nonadherence and to develop evidence-based interventions to promote dietary adherence. Improving adherence with the dietary regimen may decrease volume overload, exacerbations of HF, unnecessary rehospitalizations, and mortality as well as increase quality of life in this patient population.

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Table 1. Characteristics of the Sample (N = 20)

Age, years (mean ± SD)	60.2 ± 10.7
Male Gender (%)	60%
Marital Status (%)	
Married	55%
Widower	30%
Single	10%
Cohabiting	5%
Education, years (mean ± SD)	12.2 ± 3.5
Ethnicity (%)	
Nonhispanic White	80%
Black	20%
Annual Income Level (%)	
< $10,000	26.7%
$10,001-20,000	33.3%
$20,001-30,000	26.7%
$30,001-40,000	13.3%
Left Ventricular Ejection Fraction (%), (mean ± SD)	27.3% ± 13.9
New York Heart Association (%)	
Class I	11.1%
Class II	33.3%
Class III	55.6%
Class IV	0%